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ABSTRACT

The monograph offers three papers presented at a 1978 symposium in Arizona entitled "Foundations of Rehabilitation Planning with Deaf Persons who are Severely Handicapped." The keynote address by Ralph White presents an overview of what can and should be happening with the severely handicapped deaf population, considering such questions as who the severely handicapped are, what it requires to rehabilitate them, who is responsible for providing services to them, and whether there is a real commitment to their rehabilitation. "Services for Severely Handicaped Deaf Persons" by Dale Williamson, examines the current status of services for the severely handicapped deaf within the perspective of historical and contemporary events at the state and national levels. "The Severely Handicapped Deaf Population" by Larry Stewart, defines that population, describes its characteristics, lists its needs, describes what is being done to help the population, and outlines future possibilities for improving services for these children and adults. (DLS)

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SEVERELY HANDICAPPED DEAF PEOPLE: A PERSPECTIVE FOR PROGRAM ADMINISTRATORS AND PLANNERS

Larry G. Stewart, Editor

A Monograph of
Selected Presentations from the Symposium
"Foundations of Rehabilitation Planning With
Deaf Persons Who Are Severely Handicapped."

Tucson, Arizona, April 19-21, 1978

The Model Demonstration Program
The Rehabilitation Center
College of Education
The University of Arizona
Tucson, Arizona 85721

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FOREWORD

This publication is intended primarily for top administrative officers and program planners responsible for designing and overseeing the implementation of education, habilitation, and rehabilitation services of all kinds at the state level. However, others will find the contents interesting and helpful.

Educators and rehabilitation workers are becoming increasingly responsive to the needs of the severely handicapped, including those deaf people who are severely handicapped. At this time - 1978 - more than ever before, there is the increasing awareness that our educational and human services systems are not responding adequately to the needs of the severely handicapped deaf. Too often, too little is offered too late.

Agency leaders are unhappy with this state of affairs, yet too often they lack a meaningful perspective of the problem and its ramifications.

On April 19-21, 1978, the Model Demonstration Program for Persons Who Are Hearing Impaired and Developmentally Disabled, cooperatively with the Arizona Chapter of the American Deafness and Rehabilitation Association (ADARA) and the Arizona Department of Education (SELECT Program) sponsored a three-day symposium. This symposium, entitled "Foundations of Rehabilitation Planning with Deaf Persons Who Are Severely Handicapped," featured several timely presentations on the education and rehabilitation of this population.

Three of these presentations are singled out for publication in this monograph. Each one offers important information that agency planners will find useful as they consider new services for the severely handicapped.

The symposium keynote address was prepared by Mr. Ralph White, Program Specialist, Texas Rehabilitation Commission. Mr. White, a deaf professional, gives an overview of what can and should be happening with the severely handicapped deaf population using the theme from Dickens, "It was the best of times, it was the worst of times. . . . "

The symposium banquet address was prepared by Dale Williamson, Director, Region IX Office of the Rehabilitation Services Administration. Mr. Williamson, a long-time champion of improved services for the handicapped, casts the current status of services for the severely handicapped deaf within the

perspective of historical and contemporary events at the state and national levels.

The third and final presentation in this monograph was prepared by Larry Stewart, Project Director, Model Demonstration Program of the Rehabilitation Center, the University of Arizona. Dr. Stewart's paper defines the population and discusses some of its more pressing problems and needs. Reference is made to S. 2600 at a time prior to the introduction of its House version. Hence, although the article is timebound it is nevertheless informative.

It is the hope of the Model Demonstration Program that program administrators and planners will read this monograph and respond positively to the clear need for a new commitment toward improved services for the severely handicapped deaf population.

Larry G. Stewart, Ed.D.
August, 1978

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KEYNOTE ADDRESSS

by

Ralph White
Texas Rehabilitation Commission

I am honored and pleased to be with you folks tonight. It is especially great to be in Tucson which has during the past several years made many significant contributions to the field of deafness rehabilitation. Tonight I have, in addition to the pleasure of being here, the honor of keynoting this conference. I am not sure what this honor entails, but I can tell you that I always welcome the opportunity to spread my bias.

Most people I know attend meetings such as this because they afford them the opportunity to maintain and extend personal contact with significant people who can add to their own job effectiveness. There is nothing wrong with that, but it does seem to me that the fact this meeting is being held, in and of itself, is an indication of the need to consider some unresolved needs in the rehabilitation of severely handicapped deaf people.

Allow me to borrow a few words from the Great Book which reads in part:

To everything there is a season, and a time to every purpose under the heaven: a time to be born and a time to die; a time to love; a time to hate; a time of war and a time of peace.

Such a time faces us tonight. In considering the rehabilitation needs of severely handicapped people, we have the choice between what we have – emphasizing the same programs, doing the same easy exercises about meeting their needs – or going after better services by grappling with the real gut issues about serving this population.

In a gathering like this, there is an ever recurring problem. There is a tendency for us to become locked in our own stereotyped way of thinking. We become stuck at our own particular level of involvement with little concern for the broad implications of our task. We tend to perpetuate those programs and activities with which we are associated and to withdraw from problems and issues not within our scope of interests or responsibilities. One of the foundations for rehabilitation planning with severely handicapped people is the willingness to recognize that rehabilitation is an all-community effort.

Dickens, in the *Tale of Two Cities,* wrote, "It was the best of times. It was the worst of times."

We have to make the judgment whether this shall be the best of times or the worst of times for severely handicapped deaf people.

During the last ten or fifteen years the deaf people of America have made many solid gains on many fronts – in education, in rehabilitation, in public services, in organizational effort, to name a few. Many may say that now is surely the best of times for deaf people. But for those who can't compete in the open labor market, who don't have the faintest notion of the world of work, for whom quality rehabilitation services are nonexistent or, at best, piecemeal, watered-down and available for only brief periods of time, for whom trained, competent deliverers of services are in short supply, this "best of times" could easily be their worst.

Every coin has two sides, they say. Let's consider a few things on the negative side of our times insofar as severely handicapped deaf people are concerned.

1. There has been in the last several years a marked increase in the number of deaf children with additional handicaps enrolled in educational programs for the deaf. A famous educator said: "With the advent and use of antibiotics, improved medical and nursery care, better dissemination and knowledge concerning the needs of the deaf, we find ourselves faced with a new type of challenge – that of teaching the multiply handicapped deaf child."

This author continues to say: "Although it is beneficial to know the what of a child's disability, it is usually not the role of the teacher to be a diagnostician. In addition, it is helpful to know the why of a child's condition. But more than the what and why of a child's condition, the biggest question that looms on the teacher's horizon is the how. How can I reach this child? How shall I approach this problem?" The questions were asked in a paper written in 1958 by Hugh Schunoff, former superintendent of the California School for the Deaf at Berkeley. It is interesting to note that in 1978 we are asking the same questions.

These kids are in increasing numbers on the doorsteps of rehabilitation counselors. This has vast implications for rehabilitation planning.

2. The Rehabilitation Act of 1973 has mandated that priority for vocational rehabilitation services shall go to those with the most severe handicap. The Federal Rehabilitative Service Manual provides state agencies with detailed guidelines to assist them in achieving the goal of priority in services to the most handicapped. Additionally, it has set a national goal for the percentage of severely handicapped

individuals to be served and the state agencies are required to maintain adequate statistical data to reflect services to the most severely handicapped. It remains a paradox that this legislation has not resulted to any appreciable degree an upswing in the number of severely handicapped deaf people served by vocational rehabilitation, nor in the establishment of any significant number of realistic, well-designed programs to meet the needs of severely handicapped deaf people. This mandate is not being translated into the means at the local level to do the job of working with this population. We don't need to go far to find the reason. First, it takes money; second, when it comes to allocation of funds, deaf people usually get the short end of the stick; and finally, very few people at higher levels understand what is required to serve severely handicapped deaf people.

3. The same law gave us the Individualized Written Rehabilitation Program. Among the goals of this program are to enable the client to participate more actively in the development of his vocational goals, to understand the objectives of Vocational Rehabilitation, and what he might expect of Vocational Rehabilitation. Clients are asked to consent to and agree with a plan developed by themselves and their counselors. The assumption is that adequate communication between the counselor and the client is taking place. Yet, there is evidence that many severely handicapped deaf clients are being served by counselors who can't communicate with them, nor understand the developmental effects of deafness.

4. The consumer movement has been going on for a considerable length of time. We seldom read the newspapers or watch television without seeing some reference to consumer groups pushing for or fighting against projects or certain legislation. Handicapped citizens are banding together in ever-growing numbers and becoming politically active. We don't have such a corresponding surge of organized activity in the deaf community. I am not saying that deaf consumerism is not occurring. Very certainly, we don't see many parents actively involved in organized efforts on behalf of deaf people. Parents of the deaf have been described as "badly armed, badly equipped, and poorly motivated."

If it is not the worst of times, it certainly does not look like the best. Let's look at the other side of the coin.

1. Section 504 quietly got into the Rehabilitation Act of 1974 without any public hearings or floor debates in Congress. No one paid much attention to what appeared to be a perfunctory paragraph in that law. Yet, it is proving to be the most significant bit of legislation for the handicapped people to come out of

Congress in many years. Its concept of bringing handicapped persons into the mainstream of American life is long overdue. It is interesting to note that the first time the law was tested in court it had to do with accessibility of a deaf person to a university through the provision of interpreting services. The court ruled in favor of the deaf person. This case is better known as the Neld. Barnes Case. There has been since then additional litigation on behalf of deaf persons by the National Center for the Law and the Deaf.

2. The National Association of the Deaf is emerging as a powerful consumer organization. Many professionals are entering its ranks. It is attracting more than its fair share of Ph.D's, business people, programmers, and writers. The members have an expertise which comes from having lived with their handicap. The association is rapidly filling up with members who no longer want to offer brains just to be picked at when it is convenient for governmental agencies. They are demanding the opportunity to be a part of the system and are attempting to stress the accountability issue on all organized programs for the production and delivery of services. They no longer are willing to see that the fruits of the processes go to a selected few, but also are making certain that they go also to those on the outer periphery of society; namely, severely handicapped deaf people.

So, you might say - considering both sides of the coin - that deaf people, on the average, are not doing so badly. You might also say that, if a deaf person has his head in the refrigerator and his feet in the furnace, his condition was neither hot nor cold, just average. But a deaf person without his rightful education heritage, without his share of professional rehabilitation services provided to him at his level of understanding and meaningfulness, isn't an average or a statistic. We need to get away from the notion that the severely handicapped deaf person is a hard case to work with and that services provided him are unfeasible.

So where are we? In many ways, we are like Alice in Wonderland who didn't know her way out so she stopped to ask the Cat.

"That depends on where you want to get to," said the Cat.

"I don't much care where . . . ," said Alice.

"Then it doesn't matter which way you go," said the Cat.

Poor Allice was so confused by events in Wonderland that she couldn't specify her goals.

In considering services to the severely handicapped deaf population, several questions need to be asked:

1. Who are the severely handicapped deaf?

2. Who is responsible for providing services to severely handicapped deaf people?

3. What does it take to rehabilitate severely handicapped deaf clients?

4. What are the guiding principles for providing these services?

5. Is there any real commitment to the rehabilitation of severely handicapped deaf clients?

Who are the Severely Handicapped People?

Admittedly, this is not an easy question to answer. There is a great tendency to view deafness along some sort of graded audiological scale in which some are more deaf than others. The communication problem inherent in the disability does not always make it possible to get an accurate and thorough diagnosis of the deaf client seeking services. Because such a thorough diagnosis and evaluation is not always easy to get, things that are not easy **don't get done**. It is important that we start off on the right foot and this means paying very close attention to how we might identify this severely handicapped deaf client and his needs. It means looking closely at the psycho-socio-cultural variables which contribute to his severe handicap. This person is in need of intensive and extensive rehabilitative services. Generally speaking, he needs services beyond those normally provided rehabilitation clients.

We must realize that we are talking about a segment of our population that has an all-encompassing type of disability. This disability is not in their ears; it pervades their whole being. Unless you have had considerable experience with deaf people, it is unlikely that my emphasis that an overwhelming majority of deaf people are severely handicapped will make an impression on you.

The handicap of deafness is complicated with eductional deficiencies, social immaturity, poor personal social adjustment, and a lower level of communication skills. Often this person carries another disability as an overlay on top of his hearing loss. Rehabilitation of these clients, if it is to get anywhere, must come to grips with these problems.

What does it require to rehabilitate Severely Handicapped Deaf People?

There is too much tokenism in the field of rehabilitation as far as services to severely

handicapped deaf people are concerned. It is seen in the widespread belief that all it takes for a counselor to serve deaf clients is "seven easy lessons" in manual communication and a crash course in "psychology of deafness." This is a simplistic approach toward serving this population, but the fact is this training won't provide anyone with the magical ability to work with a really severely disabled group. Rehabilitation counselors place a high value on the ability to empathize with their clients. If we are to meet the rehabilitation challenge of severely handicapped deaf clients, we must find personnel with the ability of participating in the ideas and feelings of these clients and to marshal the resources of the community to bear on their rehabilitation. But again, we are faced with the question – what are appropriate services for this population?

Rehabilitation is traditionally thought of as a restorative process. Built into this concept is the notion that a client has resources of past experiences upon which the rehabilitation counselor can draw to rehabilitate him towards self-sufficiency. With this model client, we are not starting from scratch. However, for the severely handicapped deaf client who has never known a level of self-sufficiency, traditional rehabilitation services are frequently woefully inadequate to get the job done. This client represents a **habilitation** rather than rehabilitation challenge. What he really needs is a program geared to deal with him on a twenty-four-hour basis. It could be a rehabilitation center, a halfway house, a day program or a foster home which provides ongoing training in the nitty-gritty necessities of life such as manners, money management, socialization techniques, etc. For this client, nothing is taken for granted and the most elementary aspects of living will need to be patiently taught and continuously reinforced.

Every eligible deaf person has a right to rehabilitation services. However, service standing alone does nothing to improve the daily life of a person. It is only when the deaf person manages to access successfully to a relevant and responsive service system - that the right to services assumes any meaning.

Who is responsible for providing services to Severely Handicapped Deaf People?

It should not require too much research nor imagination to find out whose responsibility it is to provide services to this population. It lies squarely with the state agency. It has the mandate from Congress to serve severely handicapped deaf people,

but it must be accompanied by a firm commitment to gear up its administrative machinery to accomplish this.

Yet, even with the mandate of Congress, what has been actually happening in practice?

The severely handicapped deaf people are getting very little in the way of service. We hear a great deal about the quality of casework, but let me share with you an item which appeared in a study of casework practices.

> *The quality of casework is translated to mean the quality of case records. This occurs because the quality of case records is easier to measure and to monitor than the quality of services provision.*

If an agency wishes to serve deaf people effectively, it must provide a wide array of services which are not normally provided. The commitment must come first from the administration of the agency which will go all the way down to the district office level. Nothing much is going to happen without it. Sensitivity to the needs of this population and determination to meet these needs can occur only through change, responsiveness, and commitment within the agency, or else it is a lot of rhetoric that gets us nowhere.

What are the guiding principles for providing rehabilitation services to Severely Handicapped Deaf Clients?

Dr. Boyce Williams has established some guiding principles for the planning of services for deaf people. First, these services must be geared to the needs of deaf people. This means you must know your population, their needs, and the services required. Second, your programs must be geared to serve individuals. You will avoid stereotyping and generalizing in your program planning. Third, deaf people must be served by real professionals in all service areas. In the past, too much service has been of a secondary quality, a reflection of our attitudes regarding the worth of the deaf as individuals. Fourth, perhaps the most important of all – deaf people need time.

Is there a real commitment to the rehabilitation of Severely Handicapped Deaf Clients?

An agency's record of services provided to clients in quantity and quality needed to get the job done is the best indication of its commitment. It is measured by how much funds are specifically allocated to deaf clients, how much money it invests in the establishment of realistic programs for the deaf, how

much time it provides for training of personnel, and by how the management values the success of casework whether in terms of numbers or the cost of each closure. It is also judged by its special system of evaluating needs of deaf people that takes into account the support of special programs, training of psychologists, work evaluations, and other professional people who may not be part of the agency, but from whom it buys services for deaf people.

A clear manifestation of commitment is the involvement of state administrators of services for the deaf in the decision-making process regarding recruitment of trained personnel, willingness of agency to coordinate with other agencies to provide needed services, selection of people for specialized training, purchase of special equipment and materials for increasing awareness of deafness, and selection of deaf people to serve on boards or advisory committees. These are the best indicators of attitudes and interests of a state agency and its willingness to serve handicapped deaf people. The law is one thing, but action is another. This, in the long run, is the real measurement of the state agency's commitment.

During the next three days, you must identify problems in serving severely handicapped deaf people. You will need to do a lot of soul-searching since your problems, your solutions, your priorities, your leaders, and your followers are uniquely those of Arizona. To follow through and carry out these things are neither basic nor simple because much of the actual planning and the follow-up must be done by you.

Let me sum up. It can be the best of times or the worst of times for deaf people. The choice, the decision, the judgment is shared by all of us in this room tonight. With us all working together, we can earnestly seek for severely handicapped deaf people what Thomas Wolfe once wrote:

> *So then to every man his chance, his shining opportunity to become whatever his manhood and his vision will allow him to become - this, seeker, is the promise of America.*

Banquet Address

SERVICES FOR SEVERELY HANDICAPPED DEAF PERSONS

by

Dale Williamson

Rehabilitation Services Administration

"Foundations of Rehabilitation Planning with Deaf Persons Who Are Severely Handicapped," is a very appropriate title at this time for a symposium on deafness–"Foundation," with its implication of a strong basic structure with not only durability but a sense of continuation; and "Planning," with its connotation of a detailed thought-through methodology. These are certainly necessary ingredients for the extension and expansion of our national efforts directed toward reaching and serving the severely handicapped deaf.

Have we reached the point where we are ready to utilize the results of research and demonstration projects and apply them to a plan of action based on maximum coordination of all program elements to reach and serve this group?

Do we really have a national policy on the disabled on which to base this planning?

In my opinion, we have not reached this point in the evolution of our social administration policy for the handicapped. However, there are some positive signs that we may be on the verge. I will suggest the hopeful signs that I have seen as I progress with my speech.

But first, I would like to go back seven years and bring you some of the current thinking at that time of an individual who is probably more of an authority on the needs of the severely handicapped or multiply handicapped deaf than any other one individual in this country.

In a paper published in the June 1971 *American Annals of the Deaf*, our host, Dr. Larry Stewart, then Director of Services for the Deaf, Arkansas Rehabilitation Research and Training Center, says in respect to a survey of the literature:

> *Generally this literature made a definite contribution in that it uncovered the size and the magnitude of the problems involved in educating and rehabilitating severely handicapped deaf people. Yet as one reviews the scene, it become abundantly clear that the field has yet to mount a concerted, systematic attack on problems that beset these people and lack of effective teaching methodology.*

Further, he says in the same paper:

> *Finally, education and rehabilitation programs for severely handicapped deaf people have gained important knowledge concerning the problems of these people. However, only minimal attempts are made to synthesize this knowledge and make it available to other educators and rehabilitation workers with the deaf. This cross exchange of information is vital to progress and yet the gap between research and dissemination of findings remains great.*

These cogent comments, made six years ago by Dr. Stewart, are probably, unfortunately, almost as true today as they were then. Our inability to effectively utilize our research findings in program development is disgraceful. It is particularly disturbing when it relates to a group of disabled who are as underserved and as touchingly in need of our help as are the mentally retarded deaf population. I so clearly recall that over fifteen years ago, when I first started work with the Federal Office, I visited a very successful RSA-supported research project at LaPeer State Hospital in Michigan where they were then demonstrating that total communication and comprehensive rehabilitation services could help a sizable portion of the mentally retarded.

Later, I observed another such project in California which, once again, demonstrated dramatic and miraculous results from use of total communication among hospital staff and patients.

Unfortunately, there was not then a readiness within our country to pick up on these clearly demonstrated successful approaches and to mass an attack to eliminate the problem within all of our state hospitals and schools for the retarded. Not only was there a readiness, but there were not sufficient numbers of trained professionals and interpreters at that time to mount such a national effort.

There is still a shortage of professionals in the psycho-social field trained to work with the deaf as well as a continued shortage of interpreters. However, hopefully we have sufficient numbers that this will no longer keep us from moving forward from the Model Demonstration Program that Dr. Stewart now directs in Arizona toward a continuing expansion of such services across the country. We cannot rest until we are sure that every deaf person in an institution for the mentally retarded has been correctly diagnosed and has an individualized plan of services developed and implemented. Those of us at this meeting must commit ourselves to doing everything we can to insure that this movement doesn't once again terminate at the end of the project grant period. The country was not ready 15 years ago, but surely it is today.

Another large group of underserved, severely disabled deaf is the mentally ill group. For years there have been islands of effort made to demonstrate the effectiveness of professional services to this group. But this, too, has not caught on as a national effort. The work of Drs. Altschuler and Rainer started about 15 years ago in New York, and clearly demonstrated the extent of the problem and the need for services. But, oh, how slowly we have moved! In our Region, we have been fortunate to have had the ongoing research efforts of Dr. Hilde Schlesinger at Langley Porter Clinic, U.C. Medical Center, San Francisco. However, it was not until this last year that we were able to provide anthing resembling the support that was required for the activities of their Center. In one of his first official activities after being appointed Commissioner of RSA, Bob Humphreys signed an award establishing a Research and Training Center, No. 23, on Deafness and Mental Health, at the University of California Medical Center in San Francisco. The Director of this Center is Dr. Hilde Schlesinger (who, incidentally, received her orientation to deafness while an undergraduate here at the University of Arizona when she worked part time at the Arizona School for the Deaf).

In its first year of operation this center has established as its four main functions:

1. Research on psychology of deaf persons focusing on work adjustment, motivation and performance.

2. Advanced and specialized training of mental health, vocational and other professionals and paraprofessionals.

3. Clinical services for the deaf.

4. Technical assistance to agencies involved with the establishement of mental health services for the Deaf.

Hopefully, this program will continue to expand and, through its research, training, and technical assistance efforts, begin to assist other communities across the country in the establishment of clinical service facilities with trained staff and the upgrading of existing programs. However, don't expect this type of assistance from the Center immediately for two reasons: first, it is still in the organization stages, and secondly, it is receiving a minimal level of support from our office. As professionals and consumers, vigilance must be maintained in order to insure that the momentum that is started continues until we reach the point that all deaf individuals in our country have available to them mental health service of the same quantity and quality as the hearing population.

The deaf individual with serious orthopedic-type handicaps presents a unique problem particularly when that individual needs continuous and close medical supervision such as is necessary for paraplegics and quadraplegics. It is a fact that the successful, permanent rehabilitation of a spinal cord injured individual is directly related to that individual's understanding of the possible medical complications of his condition and the ability to learn prophylaxis and the ability to secure the necessary medical advice and treatment early after warning signs develop. I'm sure that most of us are familiar with any number of horror stories related to a deaf person, otherwise physically normal, attempting to secure adequate medical diagnosis and treatment. Together with the special need of the spinal cord injured for the real in-depth communication necessary to provide medical education for prevention, we have a unique and profound problem.

The Center for Independent Living in Berkeley, California is a service organization run by disabled people. They have established a section for serving the deaf in the community. This deaf service section is directed by a quadraplegic deaf man. Recently, the Brademas Committee held hearings at this Center for Independent Living and this deaf quadraplegic gave testimony. I think his testimony dramatically enunciated some of the problems of this type of double handicap. Let me quote from parts of his testimony: "I was born deaf. At the age of 24 I was in an accident. I was paralyzed from the neck down, but I didn't know what it was. After a few months, I realized my spinal cord was broken.

"At the same time, I began to get help from physical therapists. I started to exercise. The communication was limited, but I sensed that exercise would help make me more mobile.

"From the day I was in the hospital, I got a daily load of drugs and pills. I could not understand why I was getting them and what they were for. It went on for several years after I left the hospital. Nothing but pills was what I got. I had physical problems connected with my broken neck like headaches and pressure sores and went to a doctor. He gave me some pills. I never learned how to take care of my health, no interpreter for the doctor to explain.

"I was lucky; my mother took me out of the hospital. I lived with her for five years. I learned to do several things like dressing myself and driving a car. I thought I couldn't be very independent.

"Two years ago I heard about CIL. I came but it was hard to get the services. I sensed it was a good thing to move here and be on my own. Very few

people here at CIL could communicate with me, but it grew. More people learned to sign. Communication improved and I began to get better services. I learned how to take care of myself and about the medical aspects of my new disability. I also enjoyed the housing, counseling and transportation services.

"CIL has some services the deaf people could use so I helped with starting the deaf services project here. We hired two deaf people to run it. Then we got an interpreter and communication improved even more, along with more people taking sign language classes.

"I hope to become a peer counselor to help many deaf people like myself who still don't know anything about independent living. It would help if more independent living programs were open to them.

"I am also looking forward to the day when all independent living centers in the U.S. would have deaf services."

The staff in this center are in the process of trying to collect demographic material in respect to this multiply handicapped population in order to facilitate planning and delivery of services. There is no reason to believe that our deaf population is any more immune from the trauma that causes spinal cord injury than the hearing population. Hopefully, the medical acute care and rehabilitation facilities will provide the same level of care for the deaf which is resulting in an increasing number of spinal cord injured surviving the trauma and becoming candidates for community comprehensive rehabilitation services. Adding to this the spinal cord injured deaf confined to wheel chairs because of cerebral palsy or other neuromuscular disease, we undoubtedly will have a sizable population in the near future.

The many emerging centers for independent living across the country need to be stimulated to develop the services necessary to encourage the participation of the multiply handicapped deaf who need this array of services in order to learn independent living and hopefully move to the point that they can benefit from vocational rehabilitation services. For reasons we are all familiar with, many deaf groups are reluctant to join together with other disability groups in these types of community, consumer-based, independent living service programs. However, in order to secure the services necessary for the multiply handicapped deaf in the community, in my opinion, it will take this collective knowledge and strength. No single disability group can expect to generate the strength and the capacities necessary to meet the unique needs of these multiply handicapped. This will require additional changes on the part of some deaf leaders and professionals.

Frank Bowe, a deaf man, Director of the American Coalition for the Disabled, in a speech in Columbus, Ohio last year, entitled "Coming Together, Meeting the Needs of the Multiply Disabled," referred to this need for cooperation. ". . . and we are not prepared to cope with these multiply and severely disabled individuals. We have in this very room highly trained specialists in deafness, mobility impairments, blindness, and mental retardation. Yet I hardly need to stress that few of us are trained in more than one disability; few of us have the skills needed to resolve the problems of the multiply disabled people. And the programs within which we work have been designed just as we have been trained; to work with single rather than multiple disabilities. We have schools for the deaf and schools for emotionally disturbed children. But when deaf children are also emotionally disturbed, we do not know where to place them. We have counselors who are highly skilled in working with blind clients and others who specialize in mental retardation, but who serves the mentally retarded blind client?"

His speech continued to develop this theme. In conclusion he said: "We will meet the challenge only if we come together. Some of you know more about deafness than others, and some of you are highly trained in blindness. Let us see how you can come together to serve deaf-blind individuals and how about educators and rehabilitation personnel coming together with the supportive people? What about professionals coming together with the consumers?

Is it happening? Do your consumer advisory groups include multiply disabled people? Are you coming together to give the teachers and counselors of tomorrow the training they will need? Are you coming together to give the children and adults of today the help they need?"

Dr. Bowe highlights a real problem in respect to serving the multiply handicapped deaf. The deaf have had a realistically-based fear of joining other disability groups out of concern of being underserved because of communication problems. However, as we develop programs such as Centers for Independent Living, which seems to me a necessary kind of component to a community service delivery system for multiply severely handicapped, maybe it will be necessary to have this "coming together."

It is significant that this kind of encouragement comes from a deaf man who is a national leader of a coalition movement.

There is a particular ingredient emerging in these centers for independent living that I would like to refer to briefly. This is the growing use of peer

counseling; disabled counseling disabled. The dynamics of peer counseling includes the concept of role modeling. I think we need t take a much closer look at the role of peer counseling and role modeling in the rehabilitation process of the severely disabled. In the first state TRIPOD meeting that I attended, I was involved in an emotional and dramatic example of the meaning of role modeling. Professional parents of a multiply handicapped deaf daughter had the experience for the first time of seeing a deaf person participating as a main planner and speaker at a major conference. They described to me how much this meant to them in relationship to their adjustment to their child's disability. Recently, we have seen an increasing number of incidents where such role modeling has played a significant role in rehabilitation. I would hope we can capitalize on the importance of role modeling and peer counseling as we build our community delivery systems for the multiply handicapped deaf, tying together this service from the community centers to outreach into home and preschool programs for severely disabled children and their parents.

I indicated at the beginning of my remarks that I saw positive signs that would suggest some optimism regarding our ability to bring together the necessary resources at the Federal level to encourage the development and coordination of services to provide meaningful rehabilitation services to the multiply handicapped deaf. I firmly believe that our new Commissioner intends to give priority to serving these types of disabled individuals. In one of his first public statements after becoming Commissioner, Bob Humphreys said: "The Rehabilitation Act of 1973 speaks of a priority for those with the most severe handicaps, and the Congressional intent is exactly that. As a part of this effort we need to search out, find, and serve people with multiple handicaps, those with more than one disability, those who are poor and disabled, and minorities who are disabled, for example." There could be no clearer statement of RSA policy toward priority for the multiply handicapped than this strong statement.

I also believe that his reorganization of services to the disabled within the Office of Human Development, resulting in the new Rehabilitation Services Administration, is further evidence of a commitment to consolidate and coordinate all services so as to provide a maximum impact upon the type of person we are discussing at this symposium. To support this contention, let me quote from Commissioner Humphrey's statement to the Sub-Committee on Handicapped, Senate Committee on Human Resources, on the occasion of his swearing-in ceremonies on March 14, 1978: "I visualize the Rehabilitation Services Administration as a coordinative and a

supportive office. It should serve as a focal point for planning decisions that involve matters broader than the operation of RSA or Developmental Disabilities Office. By assuming a broader role, I begin to decompartmentalize the approach to services for the disabled population." He went on to say: "We do not have a national policy on the disabled; resources both human and financial must be marshalled and coordinated so that the most efficient, effective service delivery and program direction may be instituted."

Following this, he went on to put together the new organization structure called Rehabilitation Services Administration and including under his direction the Office of Developmental Disabled, the President's Committee on Mental Retardation, the Architectural and Transportation Barriers Committee, the Office of Handicapped Individuals, together with the old RSA or the State-Federal program of Vocational Rehabilitation. This new organization will enable him to accomplish his stated goal of "beginning to decompartmentalize the approach to services for the disabled population." This reorganization is a necessary step in his objective of establishing a national policy for the disabled with a priority of services to the multiply disabled. I am optimistic that his leadership will help us to accomplish this goal. However, we must keep Dr. Bowes' concept of "coming together" in mind. The new dollars for human services programs is going to be hard to find in the competitive arena of total governmental planning. Much of our goal must be accomplished by means of cooperative planning and services delivery. Social delivery systems must enhance their ability to accomplish this effective coming together in order to insure that we have the longitudinal planning and linkage of services system necessary to effectively serve these severely disabled.

In October 1961, President John Kennedy, on opening the first meeting of his new President's Panel on Mental Retardation, made the following thoughtful remarks: "The manner in which our nation cares for its citizens and conserves its manpower resources is more than an index of its concern for the less fortunate. It is a key to its future. Both wisdom and humanity dictate a deep interest in the physically handicapped, the mentally ill, and the mentally retarded. Yet, although we have made considerable progress in the treatment of the physically handicapped, although we have attacked on a broad front the problems of mental illness, although we have made great strides in the battle against disease, we as a nation have for too long postponed an intensive search for solutions to the problems of the mentally retarded. That failure should be corrected."

His leadership started a movement directed toward services to the retarded that, 17 years later, has resulted in a vastly improved system of services to that group.

Now, hopefully, we have arrived at the point that we can begin to reach and serve the groups in need that Commissioner Humphreys identified when he said as a part of this effort we need to search out, find and serve people with multiple handicaps.

THE SEVERELY HANDICAPPED DEAF POPULATION

by

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My presentation today is entitled "The Severely Handicapped Deaf Population." My assignment is to define this population, describe its characteristics, list its needs, and describe both what is being done to help the population and future possibilities for improving services for these children and adults.

Definition

"The severely handicapped deaf" is a term that emerged in the early 1970's, and was emphasized in the Rehabilitation Amendments of 1973. Yet, since then the term has meant many things to many people. This variation in interpretation, I might add, seems to be a major reason why it has been difficult for our field to reach a consensus on what needs to be done to help the severely handicapped deaf population. Lacking agreement on who we mean by "the severely handicapped deaf," it has of course been difficult to agree on how to help them.

In the 1974 Rehabilitation Amendments [Section 111. (a) Section 7 (6)], an attempt was made to further define the severely handicapped in the following manner:

> *For the purposes of Titles IV and V of this Act, such term means any person who (A) has a physical or mental impairment which substantially limits one or more of such person's major life activities, (B) has a record of such an impairment, or (C) is regarded as having such an impairment.*

Now, this definition does not actually improve our understanding of the severely handicapped in relation to the non-severely handicapped. For those of you familiar with the definition of "handicap" under Vocational Rehabilitation, you will note that this definition is similar to one of the three traditional criteria that have been used in determining eligibility for V.R. services since 1954.

Thus, it is not surprising that even today the definition of "severely handicapped" is a very general one. For example, many professionals perceive all deaf people as "severely handicapped." Of course, most of you know that such a perception is inadequate in

differentiating, for example, between a deaf person who is attending graduate school and another deaf person who is in a state institution for the mentally retarded. The differences between these two individuals are so very great that no theoretical or practical purpose can be served by calling both "severely handicapped." Herein lies one of the weaknesses in Vocational Rehabilitation legislation, for the looseness of the term "severely handicapped" has ultimately meant (1) the population to be served has been too large and heterogeneous for a fair distribution of available funds, and (2) expenditures of program funds have tended to go to the less severely handicapped due to the lower cost of serving them.

At this time, new Federal legislation is being considered in amending existing Rehabilitation legislation. Specifically, the 95th Congress is currently processing Senate Bill 2600, a bill to amend the Rehabilitation Act of 1973. Title VI of S. 2600 proposes to establish "Comprehensive Services for the Severely Handicapped." The definition of "the severely handicapped" as it is presently worded in S. 2600 (and this definition may change during legislative processing of the bill) is a most substantial improvement over prior definitions. Here is the proposed definition:

Section 202. For the purposes of this title:

(1) The term "severely handicapped individual" means an individual who has a mentally or physically handicapping condition or combination of such conditions which -

(a) is expected to continue indefinitely;

(b) indicates a need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are of life-long or extended duration;

(c) requires the provision of comprehensive services because of significant functional limitations in at least two of the following life activities:

(i) self-care;
(ii) communication;
(iii) learning;
(iv) mobility;
(v) capacity for independent living; and

(d) constitutes a substantial barrier to such individual's ability to function normally in society.

This definition is much more specific than in the past. The focus now is upon (1) permanence of the disability, (2) the handicapping aspects of the disability in society rather than primarily in the area

of employment, (3) the need for long-term treatment, care, or services, and (4)the need for a variety of services due to functional limitations in two or more important areas of life.

This definition of "severely handicapped" contrasts sharply with prior definitions as well as other terms that have been used in the past such as "multiply handicapped," "disadvantaged," "low achievers," and "severely disabled."

Characteristics of Severely Handicapped Deaf Persons

Severely handicapped deaf persons by the very fact of meeting the new Federal definition of the "severely handicapped," possess the characteristics that constitute the definition. At this point, however, some elaboration is needed to describe some of the specific characteristics of this group of deaf people.

1. **Communication**. The great majority of severely handicapped deaf persons have severe limitations in their communication skills. These limitations are manifested in the following areas:

   A. **Speech**. Most severely handicapped deaf persons have little if any functional speech. The speech they do have is usually understandable only to persons who work with the severely handicapped or to parents.

   B. **Speechreading**. Few severely handicapped deaf persons have functional speechreading skills. The skills they do possess are usually employed best with family members and professionals who work with them.

   C. **Writing**. Few severely handicapped deaf people possess writing skills that permit even marginal communication.

   D. **Reading**. Severely handicapped deaf people at and beyond the age of 16 years generally read at or below the third grade level, with some able to read only at the fourth and fifth grade levels.

   E. **Hearing**. Most severely handicapped deaf people have little usable hearing, hence auditory amplification is of little value as an aid to the communication process.

   F. **Sign Language**. Few severely handicapped deaf people are able to use Signed English. The great majority of them do use American Sign Language with varying levels of proficiency. Many do not possess even ASL skills but, rather, use gestures, pantomime, and demonstrations in their efforts to communicate. The severely handicapped deaf

who have severe motor problems are especially limited with sign language.

2. **Intelligence.** Severely handicapped deaf people as a group vary widely in their measured intelligence. Some fall in the profoundly mentally retarded range, while others have normal or above normal performance-type intelligence.

3. **Other Disabilities.** Many severely handicapped deaf people have other disabilities. These disabilities may include visual impairments, mental retardation, epilepsy, cerebral palsy, orthopedic disabilities, mental disorders, emotional disorders, and other physical disabilities. However, many severely handicapped deaf people do not have other physical disabilities but rather, represent a failure of families and schools to overcome the communication barriers imposed by deafness.

4. **Social, Interpersonal Skills.** Social immaturity and inadequacy in personal relationships characterize many severely handicapped deaf people. These attributes arise from communication deficiencies and the retardation in development that stems from inadequate family interaction and deficiences in educational approaches.

5. **Vocational Skills.** As a result of communication deficiencies, limited family interaction, and inadequacies in educational development, many severely handicapped deaf persons do not possess adequate vocational skills when they become adults. As a consequence, many are unemployed, are employed in menial and low paying jobs, or are employed in sheltered workshops where little is expected of them. The national lack of suitable postsecondary training opportunities for severely handicapped deaf persons perpetuates the employment problems of these people.

6. **Community Participation.** Most severely handicapped deaf people, lacking adequate social and interpersonal skills and generally dependent upon others, are usually to be found on the fringes of community activities if they attempt to participate at all – which many do not. Even among other deaf people, they are usually "the low man on the totem pole."

7. **Independent Living.** Few severely handicapped deaf persons are prepared for living independently in the community. Most do not possess the knowledge, skills, and experience base that would permit them to do so. Most are forced by their circumstances to live with family members, friends, or relatives.

8. **Legal Problems.** Many severely handicapped deaf persons encounter difficulty with legal issues due to their naivete with regard to law. Many are exploited by unscrupulous hearing and deaf adults, as with deaf peddlers and with deaf persons who sign purchase contracts with exorbitant terms. Sadly, many are exploited by family members in connection with Social Security benefits and other forms of assistance.

It must be emphasized that not all severely handicapped people experience all of these problems, but most experienced some of them and some deaf persons have experienced all of them.

At the same time, severely handicapped deaf people have many vocational, social, and personal assets. The severity of their problems often creates the impression that they are incapable of achieving much in life. This perception is a mistake. It is one of the barriers to quality services that must be overcome.

Needs

The needs of severely handicapped deaf people are suggested by the nature of their problems. These needs can be briefly summarized as:

1. Regional comprehensive diagnostic, evaluation, and training centers that offer services designed to prepare severely handicapped deaf adults for independent, semi-independent, or sheltered employment and living.

2. Community service centers designed to provide supportive services to severely handicapped deaf persons as they adjust to life within the community.

3. Coordinated efforts by state and local agencies to improve the delivery of services to severely handicapped deaf persons.

4. Concerted efforts by the deaf community and the general community to involve severely handicapped deaf persons as active participants in social, recreational, and other aspects of community life.

5. Efforts by education agencies and schools to remedy the circumstances that create severe handicaps among deaf persons. Certainly early identification, parent education and guidance, and proper educational planning and implementation are vital program activities in such a preventative program. Legislation is needed, too, to create preventative programs in the area of maternal and child health care.

What Is Being Done

A great deal is being done at this time to prevent severe handicaps among deaf people as well as assist deaf people who are already severely handicapped. An inclusive listing of such efforts would be impossible here. During this Symposium, you will learn about many of these program activities on behalf of severely handicapped deaf persons. Accordingly, I will not get into a discussion of local resources.

It is appropriate, however, to refer to other efforts outside of Arizona. There are several comprehensive centers for severely handicapped deaf people in the nation today. These include:

1. Crossroads Rehabilitation Center (Indianapolis)
2. Seattle Speech and Hearing Center
3. South Carolina Rehabilitation Center for the Deaf (Columbia)
4. Southwest Center for the Deaf and Hearing Impaired (San Antonio)
5. Multiply Handicapped Unit, Riverside (California) School for the Deaf
6. St. John's Mental Health Center (Santa Monica, California)

There are other programs serving the severely handicapped deaf, of course. It is accurate to state, however, that generally the severely handicapped deaf population is one of the most underserved in the nation today. No accurate figures are available on the size of this population, but authorities such as Dr. McCay Vernon and Dr. Boyce Williams have stated that from 35% to 50% of the deaf population may be severely handicapped. If these estimates are accurate, there could be more than 1,000,000 severely handicapped deaf persons in the nation today.

Possibilities for Improving Services

The nation as a whole and Arizona in particular have excellent potential for bringing substantial efforts to bear upon the challenge of serving severely handicapped deaf persons. The vast promise of P.L. 94-142 and Sections 501-504 of the Rehabilitation Act of 1973, along with the potentials of S. 2600 if it passes, can be realized if serious efforts are made in this direction for severely handicapped deaf people in the nation.

In 1974, I authored an article published in the *American Annals of the Deaf*. In this article, I described the problems and needs of severely handicapped deaf persons, and suggested activities that were needed to meet these needs. For the title of

this article I borrowed from our good friend from the comic strip, "Pogo," who once said, "We have met the enemy, and he is us."

This is a humorous statement, yet one that suggests a certain cutting truth. The reasons that we have not met the needs of severely handicapped deaf persons can be found largely in that we have not tried hard enough to do so. Severely handicapped deaf people need not be as handicapped as they are. They possess abilities and potentials that can be developed in the attainment of a useful, productive life for the individual.

In discussing the **how** of helping severely handicapped deaf persons, Dr. Boyce Williams in 1971, at the 6th World Congress of the Deaf in Paris, offered vital insight:

> *. . . too ready generalizations . . . can and do generate much stereotyping of deaf people. . . . Unfortunate limiting practices in counseling (and other services) take hold when professional thinking does not reflect the individual's total characteristics.*
>
> *Intellectual power "must" not be endowed with infinite quality for guidance through the journey of life. Other factors are important, too. Intellectual power may be likened to the super highway that speeds the traveler to his destination. It is the direct route and the easiest. However, experience emphasizes that there are many roads to Rome.*
>
> *This allegory is true of employement, too. We do accept the role of intelligence as a main factor in job performance. But there are other roads to Rome, too. These are factors in employment that balance, reinforce, or compensate intelligence. They have vital roles in job success.*

We should remember that, with severely handicapped deaf people, there are indeed "many roads to Rome." Our professional challenge is to find these roads and help severely handicapped deaf people to travel them.

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